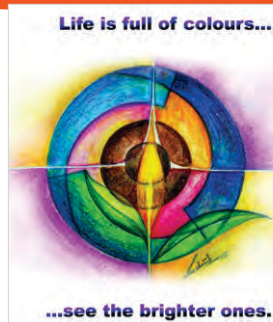




# NEWSLETTER

## Friends of Max

(July - September 2018)



FEATURE STORY: World CML Day (9/22)

# WORLD CML DAY

## 9/22

"Today, Together. Improving access."



www.themaxfoundation.org



www.cmladvocates.net/world-cml-day-9-22



www.friendsofmax.info

Every year on 22nd September the CML global community led by volunteers and patient advocates observes World CML Day. It is an awareness campaign with the support of CML patient associations the world over and members of the CML Advocates Network.

The 2018 World CML Day theme was **"Today, Together. Improving Access"**. The Max Foundation Team in the region along with volunteers from its Support Group arm, Friends of Max, conducted Patient Group Meetings in three cities Puducherry, Guwahati and Hyderabad along with Chai for Cancer Addas (*the fundraiser and advocacy drive now in its 5th year*) in Bokaro, Pune, Guwahati and Puducherry.

This was an important multi-city approach to spread awareness and build confidence in the growing CML community which is on life-long therapy. "Improving access" takes on a new meaning in this landscape of thousands of people living with cancer. It can be

improving access to treatment, to disease education, to peer support, to emotional support and to practical assistance.

In addition, a **Quality of Life Survey** was conducted among about **800 respondents, all on treatment for CML**. We have a rare window offering us insights into another world peopled by these individuals who are living with this chronic cancer. In that sense World CML Day is a celebration of the human spirit displayed by this unique family brought together by CML.

We also observe **GIST Awareness Day (GAD) on 13 July** and **World Cancer Day (WCD) on 4 February** every year. As approaches to the management of this life-long condition evolves further, physicians and caregivers and researchers adopt a more holistic approach. With access to proper treatment and advice remaining one of the biggest challenges facing the CML community it is vital to drive awareness at the 'local' level while leveraging the international reach of this unique advocacy group.

## AMMA SPEAKS

One of the demands of coping with a rare life-long cancer is riding the highs and managing the lows.

Paradoxically, this life-long condition imposes a huge responsibility on the patient. A responsibility also on his / her own family of caregivers and relatives and also to the new 'community' that the patient is now a part of. A patient of CML or GIST, simply by sharing and articulating his/her experience for others to learn from, makes a continuous contribution to the asset base called 'knowledge'. Riding the highs and living life to the full sets an example for others. Seeing a CML / GIST patient coping with such a condition and fulfilling their potential, actually living productive lives to the full, is in itself a huge boost or 'high'. "Together We Share And Learn" thus assumes greater significance for rare diseases like chronic myeloid leukaemia and gastrointestinal stromal tumour.

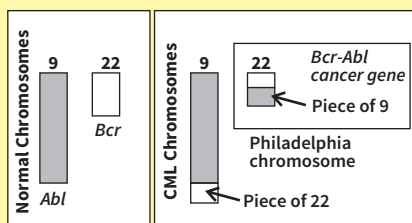
World CML Day for one and GIST Awareness Day for another, along with others like World Cancer Day, become platforms for raising the profile of such diseases by getting more and more people to be aware of the condition. Fighting stigma and improving compliance for what is a lifelong condition assumes special significance in our role as a friend and guide. Raising awareness at the micro level, among small communities of patients and caregivers in various cities across the world, gives all stakeholders the confidence and support to engage among themselves and their physicians, oncologists and haematologists.

This quarter's Newsletter features our work along with The Max Foundation on World CML Day (22 Sept) and is dedicated to the thousands of CML and GIST patients who are members of Friends of Max.

- Viji Venkatesh

## How the Bcr-Abl Cancer Gene is created

- A piece if the *Abl* gene on chromosome 9 breaks off.
- A piece of the *Bcr* gene on chromosome 22 breaks off.
- These 2 pieces switch places
- The switch leads to the cancer gene called *Bcr-Abl*.



A chronic malignant disease in which too many white blood cells belonging to the myeloid line of cells are made in the bone marrow. CML patients have what is called the Philadelphia Chromosome (Ph chromosome). Chromosomes are structures in the cells that contain genes. Every cell with a nucleus has chromosomes. Genes give instructions to the cells. The Ph chromosome is made when a piece of chromosome 22 breaks off and attaches to the end of chromosome 9. A piece of chromosome 9 also breaks off and attaches to the end of chromosome 22. The break on chromosome 9 involves a gene called *Abl*. The break on chromosome 22 involves a gene called *Bcr*. The *Bcr* and *Abl* genes combine to make the CML-causing gene called the *Bcr-Abl* cancer gene.



The Max Foundation team along with Friends of Max volunteers were in several cities organising Patient Group Meetings - with the support of physicians - stressing the importance of compliance, enabling patients to reap the benefits of access to quality treatment and care.

## How "CML Day" was born

Nearly 10 years ago, an intrepid 25 year old Canadian patient on the Advisory Board of CML Society, named Rav, first suggested that 22 September should be CML Day to symbolically wed chromosomes 22 and 9 - World CML Day was born.

## World CML Day



Mumbai



Puducherry



Hyderabad



Mumbai



Guwahati



Madurai

## World Cancer Day



Mumbai

## GIST Awareness Day

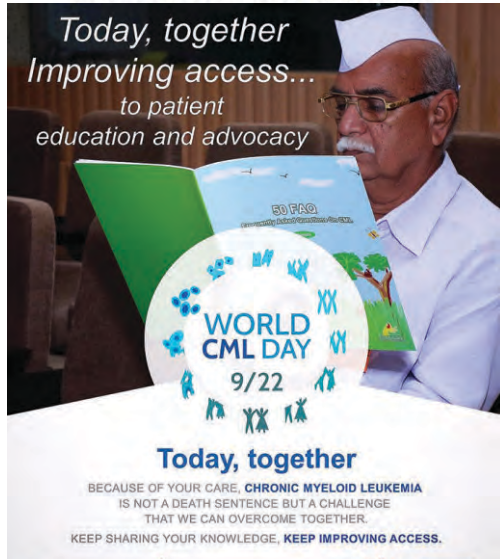
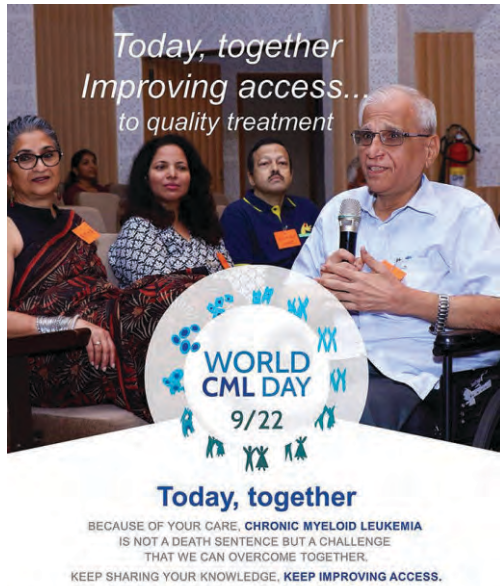


Mumbai



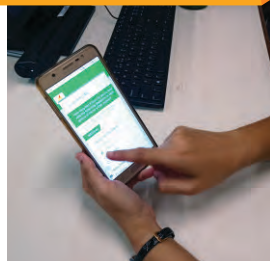
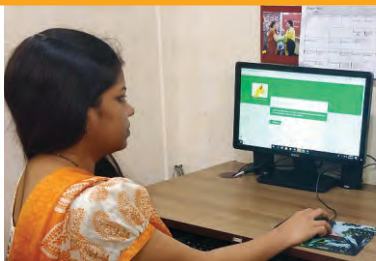
## World CML Day Posters

Posters depicting the crucial role of quality treatment, along with patient education and advocacy material, summed up The Max Foundation & FOM's year-long efforts.



## CML Survey Quality of Life

Nearly 800 patients participated in the online CML Survey. Photos show some of them answering the questions on mobiles adding invaluable information to a treasured data base.





## CML Survey Quality of Life - Living with CML Testimonials

"My life hasn't changed. My attitude towards life and other people has changed. I am have become more compassionate. I have touched more lives positively after being diagnosed with CML... that's the kind of feedback I have received from people of all age groups dealing with CML and other life situations.

CML has been a blessing for me.

The Max Foundation has laid the foundation for my life. It has given me a platform to share and care, raise my concerns, get to know other CML survivors and their story. Every individual of this group is compassionate to the core and that's what everyone needs. Glivec has been my life saver and the support group has made me look beyond CML. "

-RT

"Even though it was a little difficult personally and on my family to cope up initially, CML has made a huge impact on the way I look at the world or do things in life. It has been life changing in the sense that I'm much more determined and passionate in moving further and pretty much in doing everything.



It has made all the difference. Max Foundation and its support group arm, Friends of Max makes life much easier in every sense, starting from the support with medicines to understanding life with CML in a much better way by bringing together patients who can share their stories and support each other. This is the reason that I'm able to lead a normal life because of Max foundation."

-Priyanka Bopanna



"CML has given me and my family a better perception and understanding towards life. The Max Foundation and Friends of Max has been the biggest support ever since my diagnosis and has literally given me a second chance to lead a better life."

-Parveen Bashir



"It made me want to live life the way I want to, and not as how others want me to.

I'm lucky to have discovered a new family!"

-Nirmesh Prakash

"Living well with realisation and benefiting from a huge network of friends, the important sessions and programs held for educating patients alongwith interaction from Doctors who are at the top of their areas of interest in oncology and cancer care.

It has helped me to ride over the initial shock and look at life anew with hope and joy. It has helped me coexist with the condition without stopping myself from progressing in life and career as any non-patient. It has given me the confidence to be myself and march forward. It has given me my Viji Amma, our larger than life caregiver and bear hug therapist :-)"

-MP



only thing which stands by your side at any such real tough times."

-Apar Singh Arora

"When diagnosed with CML it came as a nightmare, but with the support of Max Foundation programme, wonderful Physicians and Max team by my side as strong pillars of support, I accepted it . One thing which changed was that I stopped taking extra tension of work and tried to come out of rat race. It became very clear that family is the

Read the complete survey results at:

<http://friendsofmax.info/home/world-cml-day-2018/>

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**To Donate:** cheques should be drawn in favour of Friends of Max and couriered to our office in Worli (Mumbai); to donate online visit [www.friendsofmax.info](http://www.friendsofmax.info); Receipts u/s 80 G of Income Tax Act, 1961 will be issued. Friends of Max is registered as a Public Charitable Trust: Regn No E-24284(B) Mumbai, dated 4-7-2007